

1. Strategies for Outreach and Education

1

Strategies for Outreach and Education

Understanding Clinical Trial Barriers

It is important to understand the reasons why so few adults with cancer participate in clinical trials. A few are listed here.

Many people with cancer, or those at high risk for developing cancer, are:

- **Unaware of the option of participating in clinical trials.** Research has consistently shown that most people are not aware that clinical trials could be an option for cancer treatment or prevention.
- **Unwilling to go against physician's advice or direction.** Research has shown if a person's doctor does not recommend a trial as an option for cancer treatment or prevention, he or she is very unlikely to participate in one.
- **Fearful, distrusting, or suspicious of research.** For many people, the idea of being "randomized" to one treatment makes them feel they have less control over their care. Many are also fearful of being "experimented upon" and not receiving treatment for their cancer. Many people distrust those in the medical community, based on past negative experiences or the historical abuses of research participants.
- **Held back by lack of access to clinical trials.** The reality or the perception that there are no trials in their local community is a barrier for many people. In addition, many people who are insured fear that their insurance company won't cover participation in a clinical trial.
- **Facing personal or practical obstacles.** There are many costs, financial and otherwise, to participating in a clinical trial. Time and travel that are required to seek care at a distant trial site may be a concern for many people. The indirect costs of being

away from work and family may also be a concern. Finally, some people may not wish to temporarily leave the care of their physician to participate in a trial.

Many doctors are:

- **Unaware of clinical trials.** Physicians are not always aware of available clinical trials. Some may not be aware of the local resources or may assume that none would be appropriate for the people they treat.
- **Unwilling to “lose control” of patient’s care.** Most doctors feel that relationships with the people they care for are very important. They want what is best for each person. Some doctors fear that if a person must be referred elsewhere to participate in a trial, they may lose control of the person’s care. They may not understand that every effort is made to maintain the physician relationship, even when a person is on a trial. In addition, many doctors may fear the loss of income if a person is referred elsewhere for his or her cancer care.
- **Under the impression that standard therapy is best.** Many physicians may not adequately understand how clinical trials are conducted or the importance of clinical research. Some physicians believe that the treatment in clinical trials is not as good as the standard treatment they might provide to people. They also may be uncomfortable admitting that there is uncertainty about which treatment is best in a phase 3 clinical trial.

Additional Clinical Trial Barriers for Ethnically Diverse Populations

- **There is long-standing fear, apprehension, and skepticism in minority populations about medical research due to real abuses that have happened in the past (e.g., the legacy of the Tuskegee syphilis study).** Among these populations, there is often widespread fear and distrust of the medical care system as a result of discrimination, indifference, and disrespect. Some may feel that they do not want to give up their rights by participating in a trial, or lose their power by being “experimented upon.” Others may be skeptical about the quality of care that would be provided in a clinical trial. Some may find that trial recruitment strategies are not sensitive to their needs.
- **Doctors may not mention clinical trials as an option for cancer care.** As noted above, many physicians do not refer their patients to clinical trials. However, some physicians may avoid suggesting a clinical trial to their minority patients, out of concern that patients would see him/her as insensitive. Moreover, some physicians may unwittingly discriminate against older patients, or those who are from certain ethnic or cultural backgrounds.
- **Many people may face additional problems accessing clinical trials.** Depending on where they live or their access to transportation, people may have difficulty getting back and forth from a clinical trial site. Those with low income may find it difficult to take time off work or find appropriate childcare. Other barriers, such as a lack of health insurance or lack of general health care, clearly present difficulties in accessing trials.
- **Cultural or ethnic backgrounds may include values and beliefs that are very different from Western medicine.** Many people have cultural beliefs that Western medicine cannot address their health concerns. Different ethnic and cultural views of health and disease (e.g., fatalism, family decisions about treatment, use of traditional healers, prayer, herbal medicines, or use of complementary/alternative health practices) may make clinical trials a less attractive treatment

option. For prevention trials, many may feel that the risk of a potential disease and its consequences may be less important than meeting daily needs.

- **Language and/or literacy barriers may make it difficult for some people to understand and consider participating in clinical trials.** The complexity of forms, including informed consent documents, may also be a barrier to those considering participation in a clinical trial. Translation can also be difficult if the person translating information has not had specialized training.

General Strategies for Educating Diverse Populations

One of the biggest hurdles for clinical trial education is overcoming suspicion of medical research.

It is important to note that strategies for clinical trial outreach and education will vary, based on the type of trial and its requirements for participation. Although some of the following strategies were designed for cancer prevention trials, many may also be used for other types of clinical trials.

Strategy 1

Educators should be familiar (and preferably a part of) the communities they are trying to reach. People who are known, trusted, and accountable will be more effective and more believable when discussing clinical trials with community members.

Suggested Steps

- Use easy to understand language. In some cases this may mean using a community's first language.
- Involve people from the community, especially community leaders. Find ways to develop collaboration and encourage ownership in the outreach program.

Tip

If you are not from the population(s) you seek to work with, it is critical that you or your organization develop meaningful collaborative partnerships with organizations from those communities.

Strategy 2

Address important concerns and perceptions, benefits, and risks about clinical trials through one-on-one contact. One-on-one contact is one of the best ways to educate others.

Suggested Steps

- Make sure you do not judge someone's values if they are different from your own. Find ways to present information that complement the values someone holds.
- Address risks and costs in a frank, open, and honest way.
- Stress the importance of enrollment in trials to the family and to future generations.
- Stress the importance of equal access to the highest quality care, including clinical trials. Each person has the right to know and understand every option available with regard to his or her health care.
- Promote the balance of spirituality, faith, medicine, and science.
- See the next section for suggested messages for specific ethnic/racial groups.

Strategy 3

Discuss potential benefits of participating in a clinical trial; but do not overlook the risks.

Suggested Step

Discuss the fact that because people are monitored closely under clinical trial protocols, they often receive a higher quality of medical care and followup than do those who are not enrolled in clinical trials.

Strategy 4

Avoid disrupting home and work schedules when conducting education or outreach activities.

Suggested Steps

- Hold meetings after church or other social activities.
- Suggest incorporating evening and weekend hours into required trial visits.

Key Points for Outreach and Education

- Clinical trial outreach strategies must incorporate an understanding of a potential participant's decision-making process, his or her culture, family and work life, and economic concerns. Those conducting education and outreach must find ways to present clinical trial information that complement the values people in the community hold.
- Education and outreach strategies should stress the importance of equal access to the highest quality care, including clinical trials. Each person has the right to know and understand every health care option available.
- Clinical trials must be explained in a way that is respectful and easy to understand, addresses someone's fears and concerns, and addresses risks and benefits.
- The research team must ensure that the informed consent process truly reflects a participant's understanding of the risks and benefits of the clinical trial. Involving family, members from the participant's community, and culturally competent staff are some ways to help verify that the participant has received the information in a way that he or she can understand and made the decision to participate voluntarily.

Specific Strategies for Educating Ethnically Diverse Populations

Research has shown that there are many differences in who gets cancer among people of different races, ethnicities, and socioeconomic backgrounds. Certain racial and ethnic groups, as noted on the pages that follow, are also more likely to die of cancer than other groups. These differences may be due to a variety of reasons, such as late stage of disease at diagnosis, barriers to health care access, history of other diseases, biologic and genetic differences in tumors, health behaviors, and the presence of other risk factors for cancer. In addition, some cancers that have a high rate of developing in one ethnic group are rare and may not be listed among the top 10 cancers in the U.S. population as a whole (based on the SEER database)*. Because rare cancers may not receive as much attention as those in the top 10, it is even more important for ethnic groups to be aware of research so that they can work to find ways to decrease the burden of these unusual cancers in their populations.

Differences in cancer screening and treatment have also been documented for people of different ages, as well as those from different socioeconomic, educational, and racial/ethnic backgrounds.

Ethnically Diverse Populations—Some Definitions

Diverse populations include minority, ethnic, and racial groups designated by the U.S. Government, including:

- American Indian or Alaska Native
- Asian American
- Black or African American
- Hispanic or Latin American
- Native Hawaiian or other Pacific Islander

*NCI's Surveillance, Epidemiology, and End Results (SEER) Program is the most authoritative source of information on cancer incidence and survival in the United States. Information on more than 2.5 million cancer cases is included in the SEER database, and approximately 160,000 new cases are accessioned each year within the SEER catchment area.

Ethnically diverse populations are growing rapidly, and according to the 2000 Census, about 25 percent of the U.S. population reported their race as something other than White.

NCI's working definition of diverse populations also includes medically-underserved populations, such as rural, low-income, and low-literacy level individuals of any racial or ethnic group. Medically underserved populations are those that lack easy access to, or do not make use of, high-quality cancer prevention, screening and early detection, treatment, or rehabilitation services. In general, these groups experience higher cancer death rates than the U.S. population as a whole.

Outreach Strategies

The strategies listed below are not meant to be a complete overview of barriers and strategies; nor should the information be generalized to all people in these groups. Attitudes within various populations vary greatly, depending on a person's age, socioeconomic status, community, and other factors. The broad outline here provides some background, context, and potential strategies for potential education and advocacy efforts.

Participation of Different Racial and Ethnic Groups in NCI Clinical Trials

Members of racial and ethnic minority groups are involved in NCI cancer treatment trials in numbers proportional to their burden of disease. However, this is not true for several screening and prevention trials. Screening and prevention studies differ in that they recruit healthy people as opposed to people with a cancer diagnosis. NCI is improving its efforts to recruit and retain minorities, underserved populations, and the elderly in clinical trials and to tailor its approaches to address linguistic and cultural differences so that the interventions developed are translatable across many subpopulations.

Source: National Cancer Institute, *The NCI Strategic Plan to Reduce Health Disparities*; available at www.cancer.gov.

African Americans and Clinical Trials

Background

A person who is Black or African American has origins in any of the Black racial groups of Africa. This definition includes:

- Native-born Black Americans
- Africans
- Haitians
- Residents of non-Spanish-speaking Caribbean Islands of African descent

Cancer in African Americans

Between 1992 and 1998, African Americans had the highest overall risk of any U.S. racial/ethnic group of not only getting cancer, but also dying from cancer.¹

From 1988 to 1992, African American men had higher rates of prostate, esophageal, oral, colon and rectum, and lung cancers than any other ethnic group.²

Between 1992 and 1998, African American men had the highest overall rate of all ethnic and gender groups of having cancer.³ In addition, in 2001, African American men were at least 50 percent more likely to get prostate cancer than were men of any other ethnic group.⁴

African American women had the second highest rates of all women of getting breast cancer in 1990-1998; they also had the highest rate of dying from the disease.⁵ From 1988 to 1992, African American women also had the highest death rates of any ethnic group of women from colon and rectum, cervical, and uterine cancers.⁶

The NCI SEER cancer incidence rates are available for different levels of racial/ethnic detail in each of the time periods (1988-1992 and 1992-1998). Although the SEER program routinely collects detailed racial/ethnic information on the cancer patients in its coverage areas, the lack of comparable detail in the racial/ethnic county-level population estimates from the Census Bureau means that incidence rates for certain racial/ethnic groups can be calculated only for time periods centered on the decennial census. For example, county-level census information for Asian and Pacific Islanders is broken down into subgroups (Chinese, Filipinos, Hawaiians, etc.) only in the 1990 decennial census.

From 1992 through 1998, the top five cancers that African Americans developed were:⁷

- Women: Breast, lung and bronchus, colon and rectum, uterine, and pancreatic
- Men: Prostate, lung and bronchus, colon and rectum, oral cavity and pharynx, and stomach

Challenges

The legacy of the Tuskegee Syphilis Study (in which researchers studied but did not treat African American men with syphilis) has contributed to long-standing mistrust in African American communities concerning clinical research. Widespread skepticism about the medical care system exists as a result of a long history of discrimination, indifference, and disrespect. The oral history contributing to this mistrust is particularly important to recognize.

Some African Americans may believe that if they agree to participate in a trial, they will not be appropriately cared for, nor honestly informed of the risks or the benefits. They may fear that:⁸

- Placebos would be substituted for lifesaving interventions
- Treatments that work would be deliberately withheld
- They would not receive a full course of treatment, especially if funding sources for the clinical trial were no longer available

Other cultural beliefs and attitudes that affect research participation include hopelessness, fatalism, and doubt about the

usefulness of cancer prevention and control.⁹ Faith, folk remedies, and the role of the family are other important influences for African Americans.¹⁰

Clinical trials may be a lower priority to African Americans and others who have a low income, less access to transportation and health care, less information about clinical trials, and low levels of literacy. Concerns about family and work responsibilities may also be a significant barrier.¹¹ African American men have noted concerns about researchers not giving back to the community, being uncomfortable talking about prostate cancer, and past negative experiences with the medical care system.¹²

Potential Solutions

Cultural strategies:

- Find people who are already active in organizations to help spread the message. People who are known, trusted, and accountable in the community will be better messengers concerning clinical trials.
- Explore partnerships with African American churches, particularly for health issues central to the mission of the church. Faith is a very important part of many African American cultures and the most successful outreach efforts usually involve churches that have two or more paid clergy, and medium or large memberships.
- Ensure that the informed consent process truly reflects the participant's understanding of the risks and benefits of the clinical trial. Involving family, members from the participant's community, and culturally competent staff are some ways to help verify that the participant has received the information in a way that he or she can understand and made the decision to participate voluntarily.

Program strategies:

- Talk about trials using one-on-one contact—preferably with another African American person—through churches, schools, civic organizations, and African American sororities and fraternities. Word of mouth is very important.

- Do outreach in person to complement other education efforts using videos, brochures, or advertisements.
- Present real-life situations that exemplify statistics or written messages. Effective dialogue can take place through a church-sponsored forum or an educational session that allows for open discussion and questioning.
- Involve local celebrities, including DJs at African American radio stations, giving them messages about clinical trials.
- Ask newspapers and local media to join in education efforts.
- Provide personalized discussion of clinical trials and followup in any education program.

Key Messages

Distrust of medical research is a critical issue, but it is important that African Americans be presented with an opportunity to find answers to research questions. The prospect of learning information that will help all people access treatment and better manage disease can be a powerful motivator.

Some African Americans may be more interested in clinical trials if they understand that participation means they:

- Contribute to their community and their families
- Join a group of people like themselves nationally, and in their local community

Clinical trial educational messages need to include information on the following topics:

- Severity of the cancer problem nationwide
- Underlying myth that African Americans don't need to be concerned about cancer
- Toll that cancer (especially breast and prostate) is taking on African American women and men—and that we don't know why
- Prevention and treatment options for high-risk African Americans—and the need for more research
- Importance of clinical trials—and what it means for all people if all groups are not represented in a trial
- Laws on participant protection and rights
- What risk means for the individual and others in his or her community

Asian Americans and Clinical Trials

Background

A person who is Asian has origins in any of the original peoples of the Far East, Southeast Asia, and Indian subcontinent. The term “Asian” refers to persons from the following and other Asian, Southeast Asian, and South Asian backgrounds:

- Chinese
- Vietnamese
- Pakistani
- Filipino
- Cambodian
- Thai
- Japanese
- Hmong
- East Indian
- Korean
- Laotian
- Bangladeshi
- Indonesian
- Sri Lankan
- Nepalese
- Bhutanese
- Sikh
- Burmese

In reaching out to Asian communities, it is important to recognize that Asians may be either highly acculturated or recent immigrants. The highly acculturated are typically born in the United States and have literacy, education, and socioeconomic characteristics that are often above the national average. On the other hand, recent immigrants and refugees tend to have limited acculturation, poor English language skills, and poverty rates below the national average.¹³ In 1990, 65 percent of Asian Americans and 12.9 percent of Pacific Islanders were born outside of the United States.¹⁴ More than half (56 percent) of these individuals reported not speaking English; and more than a third (34 percent) reported being “linguistically isolated.”¹⁵

Native Hawaiians and Pacific Islanders are often aggregated nationally into the “Other” category or currently the “Asian American/Pacific Islander or AAPI” category. “Asian Americans” and “Pacific Islanders” are two discernibly distinctive groups, comprised of numerous heterogeneous ethnic subpopulations.

These groupings have obscured disparate mortality rates that are prevalent in one group and not the other.

Cancer in Asians

Some Asians are much more devoted to traditional medical practices than to Western medicine. For example, a study of breast and cervical cancer screening in Chinese women found that more than $\frac{2}{3}$ had gone to traditional providers for preventive health care, went to temples to pray for their health, and looked to fortune-tellers for guidance.¹⁶ Another study of cervical cancer screening in Cambodian women indicated beliefs that fate cannot be changed by detection, cancer is incurable, and cancer will not develop if traditional practices are used.¹⁷

Another important educational consideration is that there may be differences in disease burden within Asian American groups because of environmental factors that are different in the United States. For example, 70 percent of Asian Americans come from countries with the world's lowest overall rates of breast cancer, yet after living in the U.S. for as little as 10 years, these women have an 80 percent higher risk of getting the disease than recent immigrants.¹⁸ In addition, third and fourth generation Asian American women have rates of developing breast cancer that are similar to their neighboring Caucasian women.¹⁹ So, while recent immigrants may not have been concerned with breast cancer in their countries of origin, educational efforts are important to make them aware of the increasing risk of this disease.

From 1988 to 1992, Chinese, Japanese, Korean, and Vietnamese* groups all had higher rates of getting liver and intrahepatic bile duct (IHB) and stomach cancers than Whites, and Chinese and Japanese had higher mortality than Whites from these two cancers, as well.²⁰ In this same time period, Korean and Vietnamese women had higher incidence rates of cervical cancer than White women. Moreover, Asian American women in general have the lowest rates of Pap test, mammogram, and breast exam screening of any ethnic group.^{21, 22}

*Liver and IHB not calculated for Vietnamese women

From 1988 through 1992, the top five cancers for many Asian groups are as follows:²³

Women

	Breast	Cervical	Colon/Rectum	Lung/Bronchus	Ovarian	Stomach	Thyroid	Uterus
Chinese	X		X	X	X			X
Filipino	X		X	X			X	X
Japanese	X		X	X		X		X
Korean	X	X	X	X		X		
Vietnamese	X	X	X	X		X		

Men

	Colon/Rectum	Lung/Bronchus	Non-Hodgkin's Lymphoma	Liver/Intrahepatic Bile Duct	Prostate	Stomach	Urinary/Bladder
Chinese	X	X		X	X	X	
Filipino	X	X	X	X	X		
Japanese	X	X			X	X	X
Korean	X	X		X	X	X	
Vietnamese	X	X		X	X	X	

Challenges

Values in many Asian cultures may be different than the Euro-American system, with decisions reached by consensus, group welfare being of primary value, and individual life not as sacred.^{23a} In some Asian cultures, the family is responsible for treatment decisions and the patient is not told of his or her diagnosis.

Many in the Asian immigrant communities need a lot of support as they learn about clinical trials, and they need to feel safe asking questions. “Saving face” in public is important. In many cases, they may feel it is disrespectful to ask questions of doctors or health professionals.

Recent immigrants also may be dealing with a combination of educational, social, and health problems, along with emotional difficulties related to separation and isolation. Many are in low-wage jobs and need to get permission to take time off work to take care of health care needs.

The language barrier also is difficult to overcome. Many Asians do not speak English, and this may not be readily apparent. There are so many Asian languages that deciding on the language(s) in which information should be printed is difficult. This barrier is particularly important in issues surrounding informed consent. The informed consent process is intimidating for all people and is especially so for those with limited English skills.

Potential Solutions

Cultural strategies:

- Assess how long the group you are trying to reach has been in this country as well as its countries of origin. It is important to fit the educational outreach to the culture and to use people from the communities to reach community members.
- Involve family members in learning about the risks and benefits of clinical trials. Sometimes children have learned to speak English more quickly than their parents, so they can be helpful in translating forms and brochures. It is important to note, however, that using children as translators may have risks. It is preferable to use someone who is trained for this work.

- Ensure that the informed consent process truly reflects the participant's understanding of the risks and benefits of the clinical trial. Involving family, members from the participant's community, and culturally competent staff are some ways to help verify that the participant has received the information in a way that he or she can understand and made the decision to participate voluntarily.

Language strategies:

- Find respectful ways to make sure that information is being understood. Someone who does not understand English may say "yes" or nod, even if they do not understand what is being said.

Program strategies:

- Use health fairs, which have been successful when organized by community members, and involve the leadership of existing Asian groups in clinical trial outreach.
- If possible, translate clinical trial information to be used in ethnic newspapers. Many immigrant groups get their health information from press that is printed in their own languages.
- Invite a professional to deliver information about clinical trials. Preferably, an Asian American doctor or nurse should be invited, who can encourage others to ask questions. Often, laypeople do not have much credibility as an information source.
- Use educational time wisely because many new immigrants from this population have more than one job.

Key Messages

- Consider the family. A family's receptivity to cancer treatments and trials will depend on the experience that relatives have had with the medical system. If a relative did not survive cancer, it may be taboo to talk about him or her. Remember to consider feminine modesty and traditional gender role values.
- Consider the impact of culture on cancer treatment decisions and be careful to select appropriate channels for education dissemination.

Native Hawaiians and Other Pacific Islanders and Clinical Trials²⁴

Native Hawaiians and Pacific Islanders are often aggregated nationally into the “Other” category or currently the “Asian American/Pacific Islander or AAPI” category. “Asian Americans” and “Pacific Islanders” are two discernibly distinctive groups, comprised of numerous heterogeneous ethnic subpopulations.

These groupings have obscured disparate mortality rates that are prevalent in one group and not the other.

Background

Native Hawaiians and other Pacific Islanders of Polynesian, Micronesian, and Melanesian ancestry made up approximately 0.1 percent of the total U.S. population in 2000. This group comprises more than 25 diverse groups with variations in historical backgrounds, languages, and cultural traditions.

Among Pacific Islanders in the United States, Native Hawaiians are the largest group, 58 percent (211,014). Three-fourths of Pacific Islanders live in the states of California and Hawaii and they are a relatively young population, with a median age of 25 years and an average family size of 4.1.

The term “other Pacific Islanders,” refers to the peoples of Polynesia, Micronesia, and Melanesia, and includes:

- Chamorros
- Samoans
- Fijians
- Tongans
- Tahitians
- Marshallese
- Chuukese
- Kosraen
- Yapese
- Pohnpeian
- Palauan
- Other Pacific Islanders

Within this group are six U.S.-associated Pacific Island jurisdictions—the Federated States of Micronesia, the Republic of Palau, the Republic of the Marshall Islands, Guam, American

Samoa, and the Commonwealth of the Northern Marianas—that have various political relationships with the U.S.

The population of the U.S.-associated Pacific Island jurisdictions is approximately 427,000. The health status varies within and among the jurisdictions, but is generally worse than for Americans. The jurisdictions must contend with health conditions found in both developing countries (e.g., malnutrition, dengue fever, cholera, and tuberculosis) and developed countries (e.g., diabetes, heart disease, and cancer).

Cancer in Native Hawaiians

For the years 1988-1992, for all cancers combined, and of all males, Native Hawaiians had the second highest cancer mortality, behind only African Americans. For males of any ethnicity, Native Hawaiians have the highest cancer mortality for non-Hodgkin's lymphoma; the second highest rates for cancers of the lung and bronchus and pancreas; and the third highest rates for prostate and colon and rectal cancers.²⁵

For the years 1988-1992, for all cancers combined, and of all females, Native Hawaiians were tied with African Americans for the second highest cancer mortality (second only to Alaska Natives). For females of any ethnicity, Native Hawaiians had the highest national mortality for cancers of the stomach and uterus; the second highest rates for cancers of the lung and bronchus; and the third highest rate for breast cancer.²⁶

Native Hawaiian males had the highest cancer death rates in Hawaii (1986-1990) for cancers of the lung, liver, and pancreas, and for all cancers combined. Lung cancer mortality rates for Native Hawaiian males were 61 percent higher than for Caucasians and 161 percent higher than for Japanese.²⁷ For Native American males during the years 1976-1990, trend data show a 62 percent increase in mortality for all cancers combined and an increase for cancers of the colon, rectum, liver, pancreas, lung, prostate, bladder, and kidney.^{28,29}

In Hawaii, Native Hawaiian females ranked highest in cancer death rates (1986-1990) for cancers of the lung, liver, pancreas,

breast, cervix uteri, corpus uteri, stomach, and rectum, and for all cancers combined. Breast cancer mortality rates for Native Hawaiian females were 25 percent higher than for Caucasians and 106 percent higher than for Chinese Americans. For cancer of the lung, mortality rates were 34 percent higher than for Caucasians and 200 percent higher than for Chinese Americans.³⁰

From 1988 through 1992, the top five cancers in Native Hawaiians were:³¹

- Women: Breast, lung and bronchus, colon and rectum, uterine, and stomach
- Men: Lung and bronchus, prostate, colon and rectum, stomach, and non-Hodgkin's lymphoma

Cancer in Pacific Islanders

Cancer surveillance and databases are rudimentary or non-existent in most of these jurisdictions, rendering cancer rates unknown. What is known is that cancer is among the top three causes of death. The most commonly reported cancers for males were cancers of the lung and prostate, and for females, cancers of the breast, cervix, and lung.

Challenges

- A history of oppression, higher prevalence of behavioral risk factors, ineffective cancer prevention and control efforts, and poor access to state-of-the-art services for cancer prevention, early detection, and treatment (including low representation in clinical trials) contribute to increased cancer risk and mortality among Native Hawaiians and other Pacific Islanders.
- Many Native Hawaiians and Pacific Islanders are socio-economically disadvantaged and underserved in terms of access to health and social services.
- In the U.S., many Pacific Islanders do not speak English at home.
- There is a general distrust of research among island communities. This distrust can also have negative consequences for those participating in a trial, such as poor compliance or avoidance.
- Geographic barriers are a problem for many Pacific Islanders; clinical trials are unavailable for most Western Pacific and Samoan communities and rural Hawaiian communities.

- Many clinical trials are lacking in cultural sensitivity and also unable to address language needs and interpret cultural behaviors and preferences.
- Many clinical trials are limited in health care services, which makes it difficult for individuals who are uninsured or underinsured.

Potential Solutions

Cultural strategies:

- Tailor the educational outreach to the culture and use “cultural brokers” from the communities to reach community members.
- Include the family unit, which for many Native Hawaiians and Pacific Islanders includes extended family members and friends, when educating about the risks and benefits of clinical trials. The role of the woman is central to the family in many Pacific Island cultures.
- Ensure that the informed consent process truly represents the participant’s understanding of the risks and benefits of the clinical trial. Involving family, members from the participant’s community, and culturally competent staff are some ways to help verify that the participant has received the information in a way that he or she can understand and made the decision to participate voluntarily.

Program strategies:

- Use personal contacts through a family member or a friend to do education and outreach.
- Explain the benefits of research to the community at large.
- Address issues of medical care that are not covered by clinical trials, as these are an important concern for participants who may not have insurance or are underinsured.

Native Americans and Clinical Trials ^{32,33}

Background

A person who is considered Native American has origins in any of the original peoples of North or South America (including Central America) and maintains tribal affiliation or community attachment.

The term “Native American” refers to:

- American Indians
- Alaska Natives:
 - Aleuts
 - Eskimos [Athap(b)asc(k)ans]

Native Americans are made up of culturally distinct and diverse communities. The U.S. contains 511 federally recognized tribes, with Native American people living in every State. The largest tribes are Cherokee and Navajo. More than 9 percent of the U.S. population reported American Indian or Alaska Native status in the 2000 Census.

Indian Health Service

There are more than 300 hospitals and health clinics, located on or near Indian reservations, run by the Indian Health Service (IHS). In recent years, many tribes have assumed management of some of these health care facilities.

The Indian clinics and hospitals are unable to provide the high-tech medical care needed to diagnose and treat cancer. For this reason, the IHS Contract Health Services program pays for Indian health care provided by non-IHS providers. However, this program is chronically short of funds. Depending on the region/tribe, its local priorities, and funding remaining in the service contract, certain treatments may not be available. At present the Contract Health Services does not reimburse for many treatments that are deemed “experimental,” which keeps many Indian people out of clinical trials.

Although 54 percent of Native Americans live in urban areas, less than 2 percent of the IHS budget is spent in urban clinics.³⁴ These clinics are severely underfunded and must rely on other sources of support, including Medicaid revenue. Many urban Indians choose to return to their home reservations for care.

Cancer in Native Americans

Cancer is the second leading cause of death among Native Americans and is the leading cause of death among Alaskan Native women.^{35,36} During 1990-1997, while cancer death rates were decreasing for every other ethnic group in the U.S., they increased 1 percent per year among American Indians.³⁷ Alaska Native women had the highest rates for getting and dying from colon, rectal, and lung cancer among ethnic groups (1988-1992), and their rates of getting cervical cancer were twice as high as those for White women. During the same time period, American Indian women had higher rates of cervical, ovarian, and gallbladder cancers than the U.S. White female population. Also during 1988-1992, Alaska Native men had the highest rates of getting colon and rectal cancer among ethnic groups and American Indian men had the highest rates of all ethnic groups of getting kidney cancer.³⁸

From 1988-1992, the top cancers in American Indians in New Mexico were:³⁹

- Women: Breast, ovarian, colon and rectum, gallbladder, and uterine
- Men: Prostate, colon and rectum, kidney and renal pelvis, and lung and bronchus

From 1988-1992, the top cancers among Alaska Natives were:⁴⁰

- Women: Breast, colon and rectum, lung and bronchus, and cervical
- Men: Lung and bronchus, colon and rectum, prostate, and stomach

Challenges

- A history of disrespect, racism, and poverty has contributed to a distrust of science and research by Native American populations. To protect the interests of Native American people, many tribes have their own Institutional Review Board (IRB), in addition to those required by Indian Health Service (IHS) or tribal facility. Successful clinical trial outreach requires that the investigator work closely with the tribal IRB in addition to those of the IHS.
- Native Americans are a culturally distinct and diverse community and their beliefs about cancer, and experiences with diabetes, alcoholism, poverty, and traditional roles can significantly affect the success of clinical trial educational programs.

- On average, Native Americans are younger, have a lower rate of high school completion, and have higher rates of poverty and unemployment than Whites.⁴¹
- Many Native people do not have access to quality health care.
- Many tribes do not have a word for cancer in their languages and historically, the disease was thought of as something that affected only the “White man.” Some Native Americans may hold a fatalistic attitude toward cancer, and fear that if they talk about cancer or even think about it, they might catch it.
- It is unlikely that Native Americans would participate in a cancer trial without hearing messages from other Native Americans, yet there are few cancer survivors to serve as role models.
- Informed consent forms and procedures may serve as a barrier to recruitment because the language used in such forms may not be well understood.
- Because of other pressing health issues, such as diabetes, obesity, and substance abuse, in addition to extreme poverty, cancer screening and treatment may not be as important to some Native people.
- There may be a tribal taboo on the loss of body parts that needs to be discussed in relation to clinical trials.
- Transportation is an important barrier for Native Americans who live in rural areas.
- Differences in communication are important to consider. Many Native Americans are reserved, reluctant to ask questions, or don’t discuss their health problems. Body language also is important, with respect for personal space and friendly gestures such as smiling and eye contact being key.
- Gender is an important issue. Traditional roles are such that women are usually caretakers and often place their needs last. In addition, Native American women value modesty and privacy, and many traditional Native American couples find a male health care provider for the woman unacceptable.

Potential Solutions

Cultural strategies:

- Use group activities such as sharing and caring for others because they are universal concepts among Native people, and should be a part of any clinical trial education program.

- Incorporate the use of traditional healing ceremonies as well as spiritual connections, which can be very important for people in these communities.
- Family plays a central role in American Indian life. The needs of the family may take precedence over the needs of the individual. When appropriate, the patient's family should be involved in the decision-making process.
- Ensure that the informed consent process truly represents the participant's understanding of the risks and benefits of the clinical trial. Involving family, members from the participant's community, and culturally competent staff are some ways to help verify that the participant has received the information in a way that he or she can understand and made the decision to participate voluntarily.

Language strategies:

- Use easy-to-understand language and a gentle approach to education and outreach. Try to include materials that portray Native Americans.
- Make sure that patient consent forms are understood. Reading out loud or encouraging consultation with others may be important.

Program strategies:

- Emphasize that participation in a trial can help improve cancer care for the next generation.
- Use stories and visual tools that focus on the family.
- Use one-on-one or small group education and outreach techniques to respect privacy.
- Work with community or tribal elders such as community health representatives and public health nurses, to find out the best ways to conduct outreach and education efforts.
- Find out if transportation is needed.
- Use public service announcements on Native American radio.

Key Messages

- Messages should be culturally relevant and discuss issues related to family and community.
- Tribal beliefs are very diverse and programs should be designed on a site-specific basis with the help of tribal advisors.

Hispanics and Clinical Trials

Background

The terms “Hispanic” and “Latino” refer to people born in North, Central, and South America, and in the Caribbean whose language is Spanish. Someone who is Hispanic or Latino is a person of Mexican, Puerto Rican, Cuban, Central or South American, or other Spanish culture or origin, regardless of race.

According to the 2000 Census, in the mainland United States today the largest groups within the Hispanic community are:

- Mexican (58.5%)
- Puerto Rican (9.6%)
- Central American (4.8%)
(Salvadorian, Guatemalan, Honduran, Nicaraguan, Panamanian, and other people from countries in Central America)
- South American (3.8%)
(Colombian, Ecuadorian, Peruvian, Argentinean, Venezuelan, Chilean, and other people from countries in South America)
- Cuban (3.5%)

The Hispanic population is the fastest growing ethnic group in the U.S. In the 2000 Census, Hispanics eclipsed African Americans to become the second largest ethnic group, with 12.5 percent of the population reporting Hispanic or Latino status. Hispanics as a group comprise many different races and ethnicities. Within these subpopulations, other differences exist according to culture, beliefs, lifestyles, and experiences, but Hispanics agree that certain commonalities go beyond specific nationalities. In general, the U.S. Hispanic population is younger, with more people per household, and has lower rates of employment, less education, and lower economic status than do Whites.⁴²

*Cancer in Hispanics**

Although Hispanics had the largest reduction in cancer mortality rates of any U.S. ethnic group (-0.9 percent) from 1992 to 1998,⁴³ they also had the greatest number of uninsured people. This is a problem because lack of access to health care leads to higher death rates and poorer health. In particular, uninsured Hispanic women are more than two times more likely to be diagnosed with breast cancer at a later stage than other women, and uninsured Hispanic men are almost four times more likely to be diagnosed with a later stage of prostate cancer than non-Hispanics.⁴⁴

From 1988 to 1992, Hispanic women were twice as likely as White women to get cervical cancer. During this same time period, the most common cancers Hispanic men developed were prostate cancer, followed by lung, and colon and rectal cancers.⁴⁵

From 1992 through 1998, the top five cancers in Hispanics were:⁴⁶

- Women: Breast, colon and rectum, lung and bronchus, cervical, and uterine
- Men: Prostate, lung and bronchus, colon and rectum, non-Hodgkin's lymphoma, and stomach

Challenges⁴⁷

- Many Hispanics have strong religious and cultural beliefs. Some may believe strongly in “fatalismo” (fatalism) and “resignación” (resignation)—that diseases or illness cannot be controlled because they are inherited.
- Many may use folk remedies [such as “uña de gato”(cat's nail)] to treat cancer or wait until they are in serious pain to see a doctor.
- In one study, barriers that were identified by Latinas considering a cervical cancer trial included transportation, fear of getting a placebo, care of children and family, and care from a male provider.⁴⁸
- Although Spanish is one language, regional dialects need to be considered when translating materials.

*“Hispanic” is not mutually exclusive from Whites, African Americans, Asian/Pacific Islanders, and Native Americans.

- The language barrier is particularly important in issues surrounding informed consent. The informed consent process is intimidating for all people and is especially so for those with limited English skills.
- Some Hispanics think that cancer treatment will only prolong life but that no effective cure exists for the disease. Even if people are treated, it is felt that the type of treatment depends on the person's ability to pay.
- Hispanics may not obtain health care until they are very sick and cannot perform normal functions. This adds to the number and severity of health problems that need to be evaluated. However, women are more likely than men to seek medical care.
- Many in the Hispanic community feel that doctors do not communicate well with them and they do not feel well informed about trials. Many hold the perception that doctors may have financial interests in a trial, and there is a lack of trust around participating in scientific research.
- A sense of fatalism and resignation is usually strongest in women and older men. This may make people feel that treatment is useless.
- Machismo is a barrier because men feel they are the family protectors and should not show weakness.
- Hispanics' biggest barriers to accessing health care are money, time, and language. Other common problems include lack of insurance, problems with transportation or childcare, and getting off work to see a doctor.
- Although face-to-face interaction is important, Hispanics would not welcome unknown health educators or volunteers into their homes. Men lack trust in a Federal Government source, while most women tend to trust it.

Potential Solutions

Cultural strategies:

- Collaborate with people who are from the communities and speak Spanish. Community members can identify with people who have a direct tie to their situation. Personal interaction is very important. Testimonials from local pastors, Hispanic celebrities, or doctors who have experienced cancer themselves are beneficial.

- Involve family members in learning about the risks and benefits of clinical trials. Sometimes children have learned to speak English more quickly than their parents, so they can be helpful in translating forms and brochures. It is important to note, however, that using children as translators has both pros and cons. It is preferable to use someone who is trained for this work.
- Ensure that the informed consent process truly reflects the participant's understanding of the risks and benefits of the clinical trial. Involving family, members from the participant's community and culturally competent staff are some ways to help verify that the participant has received the information in a way that he or she can understand and made the decision to participate voluntarily.

Language strategies:

- Find respectful ways to make sure that information is understood. When people do not understand English, they may say "yes" or nod, even if they do not understand what is being said. It is important to find respectful ways to make sure that information is being understood.

Program strategies:

- Take the outreach program out to community and neighborhood centers as well as to other sites that are already familiar to Hispanics. Consider partnering with existing groups.
- Use family-oriented, positive messages as much as possible to offer hope.
- Use radio and newspapers for outreach. Spanish-language media—especially television and radio talk shows—are main sources of health-related information. Printed materials with many pictures/illustrations and minimal text are preferred.

Information on Other Underserved Groups

Older Adults

When considering older people and clinical trials, it is important to note that approximately 60 percent of all cancers occur in people aged 65 and older, and the number of people over age 65 is expected to double by the year 2033. The elderly are an important group to participate in clinical trials.

Because of mobility problems, transportation (including escort assistance) is one of the most important challenges specific to older people. Literacy issues (see below) are also a challenge that must be addressed when educating older adults.

Fostering positive doctor-patient interaction is another difficulty because often the older population is reluctant to question or challenge doctors and may be afraid to offend by changing doctors. This is compounded when doctors do not refer older adults to trials because of the assumption that they are too old or sick for a trial.

Older persons are more likely to be living on fixed incomes, so the financial aspects of clinical trial participation may be heightened. The family, or other social support, is another important consideration because it is often involved in the older person's treatment and decision-making process.

It is important to inform older adults that Medicare reimburses for all routine care costs for its beneficiaries participating in clinical trials.

People with Low Literacy Skills⁴⁸

"Many Americans face the serious problem of not being able to read or understand information. According to the 1992 National Adult Literacy Survey (NALS), some 40 to 44 million of the 191 million adults in the United States are functionally illiterate. Another 50 million are only marginally literate. Functional literacy represents more than just the ability to read. It involves reading comprehension as well as the ability to compute, communicate, write, and solve problems. These skills are especially important for patients in acquiring general information and applying it to their specific circumstances."

“When applied to the health system, low functional literacy translates into low health literacy. Health literacy is defined as the ability to obtain, interpret, and understand basic health information and services, as well as competence and motivation to use such information and services in ways that enhance one’s health. Most health-related educational materials use simplified printed materials to convey information, assuming that people can read. Most adults do read, but many have difficulty understanding what they read and applying generalized information to their own specific situation.”

“One common assumption is that certain populations have low levels of functional literacy. For example, traditionally “underserved” populations such as those with low incomes are labeled as having low levels of functional literacy simply because they are, on average, less educated. However, low functional literacy is not defined by race, class, or even educational attainment.”

Ways to Help People with Low Health Literacy Skills

“**One-on-one assistance** is the most effective technique for educating this group. In addition to helping people gain a better understanding of the clinical trial and their health needs, one-on-one assistance fosters trust between patients and the counselors or health care professionals who help them. Comprehension should be ascertained, but not by asking, “Do you understand?” Often the “teach back” method works well.”

“**Group assistance** offers an arena in which people can obtain information from educators and through the questions asked by others in the group. This technique often supplements one-on-one counseling.”

“**Visual tools** are designed to simplify concepts such as instructions for care that are too complicated to understand in written form or through verbal communication. Visual tools are particularly useful to those who cannot read at all. Videotapes may be useful tools, but followup discussion is necessary in order to ascertain comprehension.”

Lesbian, Gay, and Bisexual Individuals

The lesbian, gay, and bisexual (LGB) community is diverse in terms of cultural background, ethnic or racial identity, age, education, income, rejection or acceptance of societal stereotypes, and prejudice. As with other minority groups, discrimination and bias can play a role in inadequate medical assessment, treatment, and prevention of LGB health problems. In addition, lesbians may be at a greater risk of cancer because of issues associated with health care access, delayed or lack of childbearing, screening, and insurance.

Little information is available about specific clinical trial barriers for the LGB population. Significant barriers that must be addressed include:

- Previous negative health care experiences
- Fear of sexual orientation disclosure
- Perceived or actual exclusion from health promotion campaigns
- Misinformation about risks and screening
- Exclusion of significant others

References

1. Ries, L. A. G., Eisner, M. P., Kosary, C. L., Hankey, B. F., Miller, B. A., Clegg, L., & Edwards, B. K. (Eds). (2001). *SEER cancer statistics review, 1973-1998*. Bethesda, MD: National Cancer Institute. [Online], Available: http://seer.cancer.gov/Publications/CSR1973_1998/
2. Miller, B. A., Kolonel, L. N., Bernstein, L., Young, Jr., J. L., Swanson, G. M., West, D., Key, C. R., Liff, J. M., Glover, C. S., Alexander, G. A., et al. (Eds). (1996). *Racial/ethnic patterns of cancer in the United States 1988-1992* (NIH Publication No. 96-4104). Bethesda, MD: National Cancer Institute.
3. Ries, et al. (2001).
4. American Cancer Society. (2001). *Cancer facts and figures 2001*. Atlanta, GA: Author.
5. Ries, et al. (2001).
6. Miller, et al. (1996).
7. Howe, H. L., Wingo, P. A., Thun, M. J., Ries, L. A. G., Rosenberg, H. M., Feigal, E. G., & Edwards, B. K. (2001). The annual report to the nation on the status of cancer (1973 through 1998), featuring cancers with recent increasing trends. *Journal of the National Cancer Institute*, 93(11), 824-842.
8. Roberson, N. L. (1994). Clinical trial participation: Viewpoints from racial/ethnic groups. *CANCER Supplement*, 74(9), 2687-2691.
9. Guilano, A. R., Mokuau, N., Hughes, C., Tortolero-Luna, G., Risendal, B., Ho, R. C. S., Prewitt, T. E., & McCaskill-Stevens, W. J. (2000). Participation of minorities in cancer research: The influences of structural, cultural, and linguistic factors. *Annals of Epidemiology*, 10(8), S22-S34.
10. Guilano, et al. (2000).
11. Brown, D.R., Fouad, M. N., Basen-Enguist, K., & Tortolero-Luna, G. (2000). Recruitment and retention of minority women in cancer screening, prevention, and treatment trials. *Annals of Epidemiology*, 10(8), S13-S21.
12. Royal, C. D., Baffoe-Bonnie, A., Kittles, R., Powell, I., Bennett, J., Hoke, G., Pettaway, C., Weinrich, S., Vijayakumar, S., Ahaghotu, C., Mason, T., Johnson, E., Obeikwe, M., Simpson, C., Mejia, R., Boykin, W., Roberson, P., Frost, J., Faison-Smith, L., Meegan, C., Foster, N., Furbert-Harris, P., Carpten, J., Bailey-Wilson, J., Trent, J., Berg, K., Dunston, G., & Collins, F. (2000). Recruitment experiences in the first phase of the African American hereditary prostate cancer (AAHPC) study. *Annals of Epidemiology*, 10(8), S68-S77.
13. Alexander, G. A., Chu, K. C., & Ho, R. C. S. (2000). Representation of Asian Americans in clinical cancer trials. *Annals of Epidemiology*, 10(8), S61-S67.
14. Lin-Fu, J. S. (1994). Ethnocultural barriers to health care: A major problem for Asian and Pacific Islander Americans. *Asian-American and Pacific Islander Journal of Health*, 2, 290-298.
15. Lin-Fu, J. S. (1994).
16. Lee, M. (1999). Breast and cervical cancer early detection in Chinese American women. *Asian-American Pacific Islander Journal of Health*, 6, 358-367.

17. Taylor, V., Jackson, J., Schwartz, S., Yasui, Y., Tu, S., & Thompson, B. (1999). Cervical cancer control in a Cambodian American population. *Asian-American Pacific Islander Journal of Health*, 6, 368-377.
18. Shinagawa, S. M., Kagawa-Singer, M., Chen, M. S., Tsark, J. U., Palafox, N. A., & Mackura, G. (1999). Cancer registries and data for Asian Americans and Native Hawaiians and Pacific Islanders: What registrars need to know. *Journal of Registry Management*, 26(4), 128-141.
19. Shinagawa, et al. (1999).
20. Miller, et al. (1996).
21. Guilano, et al. (2000).
22. Shinagawa, et al. (1999).
23. Miller, et al. (1996).
- 23a. Guilano, et al. (2000).
24. Papa Ola Lokahi. (May 1, 2001). Personal communication. Honolulu, HI.
25. Miller, et al. (1996).
26. Miller, et al. (1996).
27. Cancer Research Center of Hawaii. (1998). *Hawaii Tumor Registry data report*. Honolulu, HI; Author.
28. Cancer Research Center of Hawaii. (1998).
29. Tsark, J. U. (1998). Cancer in Native Hawaiians. *Pacific Health Dialog*, 5, 315-327.
30. Cancer Research Center of Hawaii. (1998).
31. Miller, et al. (1996).
32. Hodge, F. S., Weinmann, S., & Roubideaux, Y. (2000). Recruitment of American Indians and Alaska Natives into clinical trials. *Annals of Epidemiology*, 10(8), S41-S48.
33. Burhansstipanov, L. (Director, Native American Cancer Research Corporation). (April 2001). Interview. Pine, CO.
34. Guilano, et al. (2000).
35. U.S. Department of Health and Human Services. (1997). *Regional differences in Indian health*. Rockville, MD: Indian Health Service.
36. Lanier, A. P., Holck, P., Kelly, J., Smith, B., & McEvoy, T. (1999). *Alaska Native cancer survival report*. Anchorage, AK: Alaska Native Health Board.
37. American Cancer Society. (2001).
38. Miller, et al. (1996).
39. Miller, et al. (1996).
40. Miller, et al. (1996).
41. Guilano, et al. (2000).
42. Guilano, et al. (2000).
43. Howe, et al. (2001).
44. American College of Physicians–American Society of Internal Medicine. (2000). *No health insurance? It's enough to make you sick. Latino community at great risk*. Philadelphia: Author. Available: American College of Physicians–American Society of Internal Medicine, 190 N. Independence Mall West, Philadelphia, PA, 19106.

45. Miller, et al. (1996).
46. Howe, et al. (2001).
47. National Cancer Institute. (1996). *Communicating with Hispanic cancer patients: A focus group study*. Washington, DC: Author.
48. Brown, et al. (2000).
49. Center for Medicare Education. (2000). *Considering health literacy*. (Issue brief, volume 1, no. 6). [Online], Available: <http://www.MedicareEd.org>

Other sources utilized for this section include:

Atkinson, J., & Hartmuller, V. (1994). Strategies for minority recruitment. In *PCPT minority recruitment manual*. Bethesda, MD: National Cancer Institute.

Brant, J. (1996). Breast cancer challenges in American Indian women. In K. H. Dow (Ed.), *Contemporary issues in breast cancer* (pp. 243-252). Sudbury, MA: Jones and Bartlett.

Brant, J., Fallsdown, D., & Iverson, M. (1999). The evolution of a breast health program for Plains Indian women. *Oncology Nursing Forum*, 26(4), 731-739.

Bunn, P., & Krebs, L. (1997). *Colorado blueprint: Women and minorities in cancer care trials*. Denver, CO: University of Colorado Comprehensive Cancer Center.

Center for Lesbian, Gay, Bisexual, and Transgender Health. (2000). *Lesbian, gay, bisexual, and transgender health: Findings and concerns*. New York: Columbia University's Joseph L. Mailman School of Public Health.

Chen, A. M. (1996). Demographic characteristics of Asian and Pacific Islander Americans: Health implications. *Asian-American and Pacific Islander Journal of Health*, 4, 40-49.

Chu, K. C. (1998). Cancer data for Asian Americans and Pacific Islanders. *Asian-American and Pacific Islander Journal of Health*, 6(2), 130-139.

Haynes, M. A., & Smedley, B. D. Committee on Cancer Research Among Minorities and the Medically Underserved. (1999). *The unequal burden of cancer: An assessment of NIH research and programs for ethnic minorities and the medically underserved*. Health Sciences Policy Program, Health Sciences Section, Institute of Medicine. Washington, D.C.: National Academy Press.

Hughes, C. K, Tsark, J. T., Kenui, C. K., & Alexander, G. A. (2000). Cancer research studies in Native Hawaiians and Pacific Islanders. *Annals of Epidemiology*, 10(8), S49-S60.

Kagawa-Singer, M., Millon-Underwood, S., Burhansstipanov, L., & Munet-Vilaro, F. (1994). Nursing research and underserved populations. In *Proceedings of the Third National Conference on Cancer Nursing Research*. Atlanta, GA: American Cancer Society.

McCabe, M. S., Varricchio, C. G., & Padberg, R. M. (1994). Efforts to recruit the economically disadvantaged to national clinical trials. *Seminars in Oncology Nursing*, 10(2), 123-129.

Millon-Underwood, S. (1994). Barriers to minority participation in clinical trials. In *PCPT minority recruitment manual*. Bethesda, MD: National Cancer Institute.

Millon-Underwood, S., Sanders, E., & Davis, M. (1993). Determinants of participation in state-of-the-art cancer prevention, early detection/screening, and treatment trials among African-Americans. *Cancer Nursing*, 16(1), 24-33.

National Cancer Institute. (1997). *Talking to patients and the public about cancer clinical trials: Findings from NCI's "Science Awareness Research."* Bethesda, MD: Author.

National Clearinghouse for Alcohol and Drug Information. (2000). [Online], Available: <http://www.health.org/features/multicultural>

Paskett, E. D., DeGraffinreid, C., Tatum, C. M., & Margitic, S. E. (1996). The recruitment of African-Americans to cancer prevention and control studies. *Preventive Medicine*, 25, 547-553.

Shinagawa, S. M., Kagawa-Singer, M., Chen, M., Tsark, J., Palafox, N., & Mackura, G. (1999). Cancer registries and data for "Asian Americans" and "Native Hawaiians and Pacific Islanders": What registrars need to know. *Journal of Registry Management*, 26(4), 128-141.

Susan G. Komen Breast Cancer Foundation. (1999). Suggestions to enhance the participation of women of color in breast cancer prevention trials. In *Clinical Trial Community Outreach Efforts*. Dallas, TX: Author.

The Mautner Project for Lesbians with Cancer. (2001). [Online], Available: <http://www.mautnerproject.org/>

Thomas, S. B., Quinn, S. C., Billingsley, A., & Caldwell, C. (1994). The characteristics of Northern Black churches with community health outreach programs. *American Journal of Public Health*, 84(4), 575-579.

Underwood, S. (2000). Minorities, women and clinical cancer research: The charge, promise, and challenge. *Annals of Epidemiology*, 10(8), S3-S12.